

Health Care Needs of Children With Disabilities on Medicaid:

Results of Caregiver Survey

Executive Summary

In order to understand the health care needs of Rhode Island children and adolescents with disabilities on Medicaid the Department of Human Services and the Department of Health funded a caregiver survey. A representative statewide sample of 257 caregivers of children with disabilities aged 1-21 was interviewed from October 1997 through December 1997. Summary findings are listed below.

- Caregivers of children with physical, mental and developmental disabilities were interviewed by telephone or in person. Children with physical disabilities comprised up 35.2% of the sample; children with mental disabilities comprised 27.3% of the sample; and children with developmental disabilities comprised 37.5% of the sample.
- Measures of health status and functional limitation show that 53.5% of the children have two or more disabilities; 49.5% needed help with their personal care; 73.7% were limited in the kind or amount of activity they can do; and 7.1% were unable to take part at all in age-appropriate activities.
- Utilization measures show that 85.6% of the children had a preventive health visit in the past year. On average, children with disabilities received --2.5 preventive primary care visits; 3.4 acute primary care visits; and 18.2 specialty care visits for a total of 24.1 health care visits per year.
- Specialty care visits varied by disability type. Children with mental disabilities had twice the rate of specialty care visits as children with either physical or developmental disabilities. On average, children with developmental disabilities had 12.6 specialty care visits per year; children with physical disabilities had 15.8 specialty care visits per year; and children with mental disabilities had 29.3
- Emergency department utilization was 2,693 visits per 1000 children with disabilities. Children with physical disabilities had the highest emergency department visits rate at 4,729 per 1000.
- The hospitalization rate was 417 admissions per 1000 children. Children with physical disabilities had the highest hospital admission rate at 700 admission per 1000 children. However, children with mental disabilities had the highest number of days spent in the hospital. Of children who were hospitalized, children with mental disabilities, on average, spent 72.6 days in the hospital per year, compared to 24 days for children with physical

disabilities and only 3.2 days for children with developmental disabilities.

- Overall satisfaction with care was high; 95% of caregivers were satisfied or very satisfied with their child's last visit to the doctor.
- Caregivers of children with mental disabilities faced the most barriers to care. They were more likely to feel overwhelmed due to their child's needs, unable to work due to caretaking responsibility, unable to find child care and not able to get support from family and friends.
- The most significant unmet needs related to support and ancillary services to caregivers. These needs included parent's support groups, respite care, information on primary condition, parent education, transportation and day care. Unmet direct care needs for the child included case management, dental care and mental health counseling.

Submitted to:

Center for Child and Family Health, RI Department of Human Services

Disability and Health Program, Department of Health

A Needs Assessment Conducted by:

Jane Griffin, MPH, MCH Evaluation, Inc. June 8, 1998